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ABSTRACT

The conference on "Support for Family Caregivers" reported in this document was designed to identify, encourage the development of, and disseminate information about effective approaches for strengthening the capacity of families to care for their impaired relatives. The first of two presentations in the opening plenary session reviews the needs and problems of families with developmentally disabled children, discusses state-level family support programs, assesses related policy issues, and explores private sector alternatives. The second presentation points out that over 75% of primary caregivers are female and suggests new and improved services which agencies might offer to family members. Four related group sessions deal with alternative ways of accessing services/products, relieving caregiver stress and providing respite, caregiver education and training and support groups, and how families are managing. A second set of plenary session presentations addresses the following topics: caregiving in Great Britain, consumer-directed preventive services, data on caregivers to the disabled elderly, and channeling as an intervention in which comprehensive case management allocates appropriate community services to the elderly while allowing them to remain in their own homes. Two final group sessions discuss private sector foundation and small business support for family caregiving, and public policies and family caregiving. A list of participants is appended. (JW)

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Family Caregiving Project

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DEPARTMENTAL WORKGROUP MEMBERS

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FORWARD

The U.S. population as a whole is aging. And with age comes an increased risk of illness and impairment. The number of people who experience chronic health problems and functional impairments is growing.

The number of developmentally disabled infants is increasing, largely as a result of the use of drugs and alcohol among pregnant teenage women. Greater numbers of mentally ill individuals are remaining in their own homes and communities.

Thus, many more people need some assistance in caring for loved ones if they are to continue to live independently.

Family members are the primary care providers for all populations who require some help. Families want to care for their impaired relatives. And people who need care prefer to be cared for by family members because they can handle crises and reach quick decisions when necessary. Equally important, a family relationship is a reciprocal one -- so the person in need of care does not feel totally dependent. They return love and support in a family relationship.

However, the ability of family members to be caregivers is challenged by the circumstances of today's world, and the availability of family caregivers to provide daily care is decreasing. More women, the traditional caregivers, are now working. They can no longer serve as unpaid caregivers. Yet neither the family nor government can afford to pay the cost of continuous formal services. Those of us in the Office of Human Development Services and our colleagues throughout the Department of Health and Human Services recognize this problem, and are committed to finding solutions.

To respond to the needs of families with an impaired or ill member, the Office of Human Development Services has developed the Family Caregiving Project. The purpose of this project is to help all grantees who have been funded through HHS research and demonstration authorities to coordinate their efforts and work with other professionals, paraprofessionals, and volunteers who are concerned about supporting family caregivers. The grantees are trying to identify, encourage the development of, and disseminate approaches for strengthening the capacity of families to care for their impaired relatives.

One activity of the Family Caregiving Project was to sponsor a Conference on Supporting Family Caregivers. This conference held on June 23-24, 1986, brought together 30 grantees funded by a variety of agencies within the Department of Health and Human Services, three private foundations, eight national professional and voluntary associations, and a host of other interested organizations and individuals. These proceedings are the result of that conference.

Conference participants identified areas for future research and policy analysis that the Department needs to conduct. They also suggested that government agencies and professional/voluntary organizations need to do a better job of informing caregiving families and the people working with them about the options for help that currently exist.

As a result of our joint identification of needed activities, we pledged to work together to share information and provide better training for professionals, paraprofessionals, and volunteers. These conference notes are an initial effort to share information about what we know. I look forward to our continued efforts on behalf of caregiving families.

Jean K. Elder

Jean K. Elder, Ph.D.
Assistant Secretary-Designate
for Human Development Services

As Adam grows older, he becomes harder to deal with at home and we need more services to keep him at home. We are finding that the 20 hours of respite services we are now allotted are totally inadequate in helping us with daily care -- diapering, dressing, bathing, toileting, feeding, etc. There is also tremendous pressure from his school, doctors, therapists and from our own sense of responsibility for us to try to do everything, but we just don't have the time or energy to do it all.

It is truly outrageous that if we place Adam outside of our home, he will receive more services than he gets if we keep him at home. In placement, he would get full SSI benefits, further financial assistance from the regional center, full medical and dental care, free diapers delivered to the door, free transportation to free community activities, free equipment and free attendant care.

Beverly Bertaina from Sebastapool
Hearing Before the Select Committee
on Children, Youth and Families, 1985

MONDAY, JUNE 23, 1986

OPENING PLENARY SESSION

OPENING REMARKS BY THE HONORABLE DORCAS R. HARDY

FORMER ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT SERVICES

Welcome to our conference on supporting family caregivers. I am glad to see so many organizations represented here today. We have 30 grantees, three foundations, and eight national associations. We have also included a number of other interested organizations.

The changing structure of the U.S. population (an increasing proportion of older people), greater family responsibilities (working women, women caring for young children and aging parents), and improved technology that allows impaired individuals to live more independently have made caregiving a more difficult task for families.

This conference constitutes an important recognition that family caregivers represent our nation's primary resource. As you know, family caregivers provide 80% of the care needed by individuals with chronic health and mental health problems. It is family members who help relatives recuperate from acute health crises and provide on-going services to those who need them.

Our purpose here, today, is to focus on the caregiver. Caregivers have not always had their own needs addressed adequately. Our primary concern has been the development of an adequate system of in-home and community based care for the impaired individual. Caregivers become vulnerable to physical and emotional stress, economic pressures, family discord and reduced performance on the job. By focusing on the caregivers we are not seeking to create two separate services systems -- one for the family member in need of assistance and another for the caregiver. Rather, we want to support the family unit in its entirety by helping all family members find ways to meet their individual needs and still function as a supportive family unit.

This conference allows us to share some of the latest information about caregiver needs and provides an opportunity to identify critical priorities for the next few years. I believe that by working together during the next two days, we will be able to develop mutual goals for supporting families that will alleviate their stresses and allow caregiving to be a gratifying family involvement rather than a burden.

Good luck in your deliberations.

STATE SUPPORT FOR FAMILIES OF PERSONS WITH DEVELOPMENTAL DISABILITIES

Valerie Bradley

I appreciate the opportunity to speak to you this morning about issues that as recently as five years ago were still regarded as marginal and certainly not in the mainstream of policy development in the field of aging or disabilities. Although I will concentrate my remarks on support services for families providing care to children with developmental disabilities, I believe that most of the issues are similar to those confronted by families coping with the needs of an elderly relative or a relative with mental health problems.

In the next 30 minutes, I would like to cover a variety of factors that have contributed to the increasing attention to the problems confronting families with developmental disabilities and also the constraints that need to be overcome in order to develop more responsive policies for family caregivers.

First, I would like to review the reasons why the plight of families providing care at home has finally begun to penetrate our consciousness;

Second, I would like to talk about the general and specific needs of families;

Third, I would like to review what has been done at the state level to support families;

Fourth, I would like to briefly assess the issues facing state and federal policy makers interested in expanding family supports; and

Fifth, I would like to explore some private sector alternatives in the area of family support.

As recently as the 1960's, the accepted practice of pediatricians and social service professionals was to recommend out-of-home placement to parents of children with developmental disabilities. Though the majority of parents with developmentally disabled children did not follow this advice, many did. Moreover, those who chose to maintain their disabled children at home did so without any public support. Today, parents are no longer automatically prompted to secure and out-of-home placement. Instead, there is a greater emphasis on the encouragement of home-based placement and support of such placements through a variety of specialized programs.

The impetus for family-based care stems from two major ideological tides. The first is "normalization", and the second is mainstreaming. The emergence of these moral imperatives coincided with a variety of other events that both helped to clarify these ideals and shape their implementation, including the following:

- Mounting research on the debilitating effects of institutionalization and on the positive effects of home and community-based care;
- Litigation -- especially in the federal courts -- to bring about improvements in institutional care and ultimately to secure services in the community in the "least restrictive setting";
- A growing body of literature supporting the "developmental model" which shows that persons with developmental disabilities can grow and learn;
- Increased evidence which shows that parents can be taught specialized skills to meet the extraordinary needs of their developmentally disabled children (See English, 1984); and
- The growing consumer movement and the creation of politically active parent groups around the country (e.g., Association for Retarded Citizens) and the recognition that many persons with developmental disabilities can participate in the service planning process by acting as their own advocates and providing reliable information regarding their needs and desires.

Family support policy has also been spurred by a recognition of the current perverse fiscal incentives that influence the decision to move a family member out of the home.

Two negative incentives can be found in the Supplemental Security Income (SSI) and Medicaid (Noble, 1981) policies. Under present deeming rules, the income of parents is treated as though it were available to the SSI or Medicaid applicant or recipient as long as she/he is living with the family. Moreover, if the level of parent income surpasses the income eligibility criteria, the child does not qualify for SSI or Medicaid. In contrast, the parent's income is not deemed to be available to a child while she/he is residing in an out-of-home facility. Given these conditions, parents with children who have costly habilitative and/or medical needs may find out-of-home placement to be in the best interests of the child and family.

States may pursue three relatively new federal opportunities to create positive incentives for home care.

- The Medicaid Home and Community-Based Waiver Program provides that states may seek a Secretarial waiver to provide a wide range of home and community-based services not otherwise available under Medicaid. The waivered services must be targeted exclusively to individuals who would otherwise be inpatients of Medicaid certified skilled nursing and intermediate care facilities. States must provide assurances that are satisfactory to the Secretary before such waivers are granted. Among these assurances are that the health and welfare of clients will be protected under the program and that Medicaid costs with the additional services would be no greater

than had the waiver not been granted. Moreover, as part of their Medicaid Waiver application, states can propose to apply deeming rules applicable to persons living in institutions to potential recipients of Medicaid-financed waiver services who are living with a legally responsible relative. To date, 20 States have elected to apply institutional deeming criteria on behalf of persons living at home with relatives.

- The Model Waiver Program is a short, expedited method for obtaining a Medicaid Home and Community Based Care Waiver. It is targeted to individuals who would otherwise be financially ineligible for medical assistance at home because of the income of their parents or spouse; but who are Medicaid eligible when institutionalized. This waiver procedure was developed to replace the Katie Beckett waiver program. This program was instituted after President Reagan highlighted the situation of a child hospitalized at substantial expense to the Medicaid program. Her parents' income disqualified her for the Medicaid program, yet was inadequate to pay for the care.

- The Tax Equity and Fiscal Responsibility Act. Beginning in October, 1982, states could apply to provide SSI and Medicaid coverage to persons under 18 years old who would be eligible for such services, if they were living in a medical institution. Eight states and one U.S. territory currently offer such coverage.

Family support policy is gaining prominence because of a growing recognition of the role played by families. Historically, the families of persons with developmental disabilities have been viewed as more of an impediment to the habilitation of their family member than as a potential care-giving resource. The author of a relatively recent article in a reputable academic journal epitomized the condescending attitude that some professionals have traditionally reserved for parents: "We cannot assume that families have the intelligence, values, education, motivation or interest to enable them as a unit to proceed as a cooperative member in decision-making." Instead of assisting families to understand the nature of their child's needs and the steps they might take to help them, many professionals counselled out-of-home placement.

What Do We Know About the Needs of Families?

As many as 90% of persons with developmental disabilities live in their homes. Though the absence of a comprehensive national data base regarding the number and demographic characteristics of caregiving families remains a concern of policy planners, much has been learned about the effects of disability on a family and the needs of persons with disabilities. Such information can be used to gain an understanding of what support families require to provide effective family-based care.

The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary challenges:

- Shock or numbness, denial, grief, shame, guilt and depression;

- Chronic stress;

- Social isolation;
- Financial cost;
- Extraordinary time demands involved in providing personal care to the family member with disabilities (e.g., feeding, washing, dressing);
- Physical stress (e.g., ambulation, lifting, carrying)
- Mental or emotional stress in handling socially disruptive or maladaptive behavior;
- Lack of the skills needed as coping mechanisms in potential emergencies (Agosta and Bradley, 1985);
- Marital discord stemming from the on-going burden of long-term care; and
- Absence of needed community support.

What are States Doing to Meet Family Needs?

To get a better understanding of the move to provide support to families providing home care for persons with developmental disabilities, the Human Services Research Institute and the National Association of State Mental Retardation Program Directors undertook a national survey of existing statewide family support programs.

Information was collected from all 50 states, although the results are somewhat clouded by differences in state definitions of family support. With that in mind, all states but Oklahoma noted the presence of a family support program. Table i (on the next page) displays the states that report the existence of a family support program according to the administrative category that best exemplifies each state's support system.

Though numerous states report the existence of a family support program, I would like to concentrate on the characteristics of 22 states with the most "extensive" systems.

Eligibility Criteria. All states impose eligibility criteria of some kind, but these criteria vary by state and can be sorted into three categories:

- The first type is client characteristics such as disability type, age, or severity of disability.
- A second type pertains to family resources. In seven states, service availability or cost to the consumer is made contingent on some type of means test, such as a sliding scale, or on some judgment of the family's capacity to cover the costs of care.

Table 1: States Offering Family Support Services

by Primary Administrative Category

Cash Assistance Programs

Connecticut	Minnesota
Idaho	Nevada
Illinois*	North Dakota
Indiana	South Carolina
Louisiana	

Supportive Service Programs

Alabama	Kentucky	Oregon
Alaska	Maine	Pennsylvania
Arizona	Massachusetts	South Dakota
Arkansas	Mississippi	Tennessee
California	Missouri	Texas
Colorado	New Hampshire	Utah
Delaware	New Jersey	Vermont
Georgia	New Mexico	Virginia
Hawaii	New York	Washington
Iowa**	North Carolina	West Virginia
Kansas	Ohio	Wyoming

Combination Programs

Florida	Nebraska
Maryland	Rhode Island
Michigan	Wisconsin
Montana	

* The Illinois state legislature has ratified a bill to permit operation of a cash assistance program but has not yet appropriated funding for the approved program.

** The Iowa State Developmental Disabilities Council had funded a cash assistance program since 1981 but terminated funding on 9/30/84. The state does provide certain supportive services.

- The third type involves consideration of the placement status of the person with disabilities. Six states prefer that the person be at risk of an out-of-home placement, while three states require that the person must be returning home from such placement. Rhode Island stipulates that to receive a cash subsidy, the family member with disabilities must have been a resident of a state residential facility for 90 days.

Client/Family Expense Limits. 16 states set some specific limit on the amount of money that can be expended annually on individual families. Though six states indicated that no limits exist, officials in these states readily admit that the total program budget naturally restricts the amount that can be spent and that costs must be held "within reason."

Number of Clients/Families Served. States with the greatest population densities tend to serve more families than states of lesser population density. For example, California serves the most families (35,000) while Connecticut and South Carolina operate the smallest programs (15 families). The total number of persons served by the programs profiled is 61,963 (exclusive of those served in Ohio because such figures were unavailable at the time of the survey). This figure may not reflect potential demand. Most people with developmental disabilities live at home with their natural families.

Appropriation Levels. Appropriation levels ranged from $21,000,000 for a "combo" program in Florida serving 8,229 families to $23,000 for cash assistance programs serving 15 families in both Connecticut and South Carolina. Cash programs are generally funded at lower levels than either supportive services programs or combination programs ("combo") which combine cash and services. "Combo" programs generally receive the most fiscal support.

Table II illustrates the services that are permissible in 22 states. In addition to these services, at least 11 states have provisions for families to acquire services that are not regularly permitted. For example, families in Pennsylvania can present extraordinary service needs to local review boards. Though state guidelines influence decisions, these review boards may ratify the provision of unique services.

Table II suggests significant variance among states regarding the range of services offered. The services noted most frequently are temporary relief or respite care (21 states) and adaptive equipment (20 states). The least noted services are information and referral and room and board for family members (two states). Maryland and Nebraska offer the most comprehensive array of services (14 services).

To follow up the survey, we went to six states to observe the conduct of family support programs -- the states were Florida, Rhode Island, Ohio, Pennsylvania, California and Michigan. The strengths and weaknesses of these programs are discussed below.

Table II: Permissible Services in 22 Family Support Programs

SERVICES	STATES																						
	CA	CT	FL	ID	IN	LA	MD	MI	MN	MT	NB	NV	NJ	ND	OH	OR	PA	RI	SC	VT	WA	WI	TOTAL
Adaptive Equipment	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X			X	X	X	X	X	20
Educational or Therapeutic Services for Disabled Persons (examples include physical, speech or vocational therapy, behavior management)	X	X	X	X		X	X	X	X	X			X	X		X	X	X	X	X	X		17
Transportation	X	X	X	X	X		X	X	X	X	X	X		X		X			X		X	X	16
Medical or Dental Services	X	X	X	X	X	X	X	X	X		X			X				X	X			X	14
Housing Modifications	X		X	X		X	X	X	X		X			X	X		X	X	X			X	14
Special Clothing	X	X	X	X				X	X			X		X						X		X	10
Diet or Nutrition Services			X	X		X	X	X	X			X		X	X							X	10
Diagnosis and Assessment	X		X	X				X	X	X	X			X								X	9
Medications		X	X			X	X	X	X		X								X				8
Home Health Care				X		X	X	X			X	X											7
Personal or Attendant Care	X					X	X	X			X												5
Recreational Services			X	X										X			X					X	5
Information and Referral										X						X							2
Temporary Respite or Relief	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	21
Family Training or Counseling	X	X	X	X		X	X		X	X	X			X	X	X	X	X				X	15
Homemaker	X						X		X		X		X				X	X					7
Chore Services	X						X				X												3
Housekeeping	X						X				X												3
Room/Board for Family (for traveling related to provision of care)			X								X												2
TOTAL	13	8	13	12	4	10	14	12	12	7	14	5	5	12	5	4	6	7	7	4	4	10	
Provisions for permitting unique services not available elsewhere	X	X	X	X	X		X	X		X							X		X			X	11

Strengths of Family Support Programs

Cash subsidies were highly rated among family members because of their individualized character. Instead of a preset menu of services, subsidies make it possible for family members to determine their own particular service needs.

With respect to service organizations, those programs that included family members at all stages of service planning and provision were seen as being more responsive to the needs of families. Further, there was a strong consensus that the presence of respite and other forms of parental assistance were crucial to the well-being of families coping with the care of seriously disabled family members. Those programs that offered both a wide range of possible support services and a flexible schedule of service delivery were also seen as being the most valuable.

Finally, family support programs were seen as preventing or delaying out-of-home placement for a person with disabilities.

Weaknesses of Family Support

The major weakness noted in some of the states resulted from the bureaucratic character of some of the programs. Specifically, clients of the Home Aid program interviewed in Washington felt that respite schedules were inflexible and required family members to plan "crises" well in advance.

Another recurring weakness noted in some of the states was the imbalance between the supply of and demand for services.

Finally, the arbitrary exclusions of groups of persons with disabilities and their families who could benefit from family support services was a concern expressed by many.

What Are the Criteria Currently Used for Designing a System?

- First, eligibility. Most states limit eligibility to certain disabilities. Some states grant eligibility to persons at risk of institutionalization.

- Second, type of program. Programs can provide cash, in-kind supportive services, or a combination of both ("combo"). A cash program is more flexible and tailored to individual family needs. An in-kind supportive services program is less flexible, but guarantees that certain services will be available. The combo program offers the best of both worlds.

What Additional Criteria Should Be Used When Designing a System?

- The program should provide families with multiple service options.

- Provide families with timely and long term support.

- Be especially responsive to the needs of young families and families with extraordinary caregiving responsibilities.

- Work in tandem with policy designed to foster development of community based residential alternatives to the family.
- Take seriously the view of the family and person with disabilities regarding how services should be designed and delivered.
- Treat the person with disabilities not as a passive recipient of services but as someone who has personal rights and who should participate in service planning in order to develop as an informed self advocate.
- Embrace practices that promote, not discourage, increased family independence from the formal service system.

CAREGIVING - WHO - WHEN - WHY

Mirca Liberti

Louise Fradkin, President and co-founder of CAPS defines caregiving as, "a euphemism for an unpaid female relative of an elderly person." Judging from my personal experience (I took care of my late father for ten years) and my daily contact with caregivers of aging parents, I support Louise's definition.

Who is the Caregiver?

In spite of the increased number of male caregivers, over 75% of primary caregivers are female. The only daughter or child; the single daughter; the wife of the only son; the sister; a relative; or a neighbor may become caregivers.

It is not unusual for a family to elect one family member to assume the role of caregiver for a variety of reasons. For example: the daughter who is not working, but who may have a family and household; the dynamic daughter who is always willing to help and is successful at it; the daughter who is geographically closest; or the daughter who has been the family's favorite.

For a middle age woman going through life changes and experiencing stresses within her own family, caregiving becomes an exasperating experience. For example, changes being experienced include: job change; retirement; empty nest syndrome; and mid-life crisis. With all this going on, the female caregiver begins to feel trapped. Guilt, frustration, anger, and resentment begin to rise.

Besides the psycho-social stresses, the caregiver experiences the frustration of trying to gain access into the bureaucratic social service system. Why frustration with the system? Have you ever tried to obtain services? Even you professionals, who know the system, probably get frustrated. But for someone who is desperately trying to get information or services, many phone calls may be necessary. Sometimes, six or seven calls are made before the correct office is obtained.

In my opinion, the lack of knowledge on the part of professionals is the most distressing aspect of trying to locate available services. I found there were many agencies providing the same types of services, some to a lesser or greater degree. Wouldn't it be more cost efficient and effective to open the lines of communication so that agencies know exactly what is already being offered? This would eliminate duplication of existing services and permit organizations to provide unmet needs through new services.

Another problem caregivers are faced with is the attitude of the medical profession toward the elderly. The family finds that medical professionals do not understand caregivers' problems and are not supportive. Seniors tend to "jump" from doctor to doctor getting different medications. How adequately do doctors monitor medications? Do they order necessary periodic blood tests to determine blood levels when certain medications are being prescribed? The answer is no -- adult children find themselves becoming ombudsmen for the parent, asking for tests, etc.

How about the Medicare maze? If Medicare is to really address the medical needs of the elderly, some provisions should be considered to improve the implementation, delivery and payment systems. Some areas to be addressed would be:

- Encourage medical schools to train geriatric specialists.
- Take a holistic view of the medical problems of the elderly and handicapped rather than a partial one.
- Require improved reviews of in-patient and out-patient health care.
- Improve access to acute and long-term care.
- Most Important -- Improve communication and coordination of services among providers of the health care system.

Legally, Medicare doctors who accept assignment should not seek other fees. However, some prey on the family to make up the difference. Family members become intimidated when bills arrive because they are not familiar with Medicare regulations. Doctors participating in Medicare should have their billing procedures carefully scrutinized.

Since we know that Medicare/Medicaid and private insurance cover only a minimal amount of services (and perhaps should cover more), the family must assume the role of the service delivery system. Thus, families are the major source of caregiving, providing 80-100% of help to the elderly.

The caregiving role begins without a family even realizing that eventually it will become a full-time responsibility.

Mom is independent, doing well, so we check in with Mom occasionally with a phone call or brief visit. She is pleasant and appreciative. She enjoys an occasional visit, weekend, or holidays with the family.

As Mom's health begins to fail, more responsibility falls on the adult child -- for companionship, transportation to medical appointments, shopping, housecleaning, bathing, and financial management.

As conditions worsen, the family finds itself faced with the dreaded and difficult decision -- Who will take care of Mom?

With some help, Mom will do best psychologically and emotionally in her own familiar surroundings. She wants to remain independent. This living arrangement can be stressful for the family and funds may not be available for adequate in-home services.

Consequently, the family might have to deal with the dilemma of choosing a home, securing funding, and preparing the family member for the change which is not usually well received.

Why Caregiving?

We have been socialized, even raised to believe that we are expected to care for our parents. Ethnic and religious factors sometimes dictate the decision to become a caregiver -- certainly financial situations may play a major role in who will care for the elderly family member. However, nowhere have I found it written that caring for a parent means destroying one's family relationships and life.

It is best to study all living arrangement options before deciding to bring the elderly family member to live with adult children. A family's desire to provide for an elderly parent in an adult child's home can sometimes be a more destructive than positive move; and even the most close and loving relationships begin to suffer once an elderly family member moves in.

My professional experiences, my work with CAPS, and my personal experiences (I took care of my father for ten years, providing him with quality of life at home by depleting his life savings), have convinced me to support the following idea. The government must not only continue to provide and expand existing medical programs, but must work with the private sector to help regulate policies regarding the newly emerging long-term care insurance which some private insurance companies are offering.

There is also a need for some federal watchdogs to regulate policies regarding admissions to long-term care facilities as well as life care communities.

The private sector can help the caregiver by providing not only child day care, but adult day care centers also. This would probably give the caregiver less stress knowing her family member is being cared for on the premises, and corporations should relax absentee policies so that a caregiver would not be financially penalized if she had to take a day off for the elderly person's needs.

Finally, the family might receive tax credits, exemptions or cash assistance for both child and adult day care, as well as for the handicapped.

In conclusion, I would like to share this family anecdote which will summarize a caregiver's plea.

One day, after a long difficult day at school where I taught emotionally disturbed and learning disabled children, I returned home totally drained. My Dad's aide left when I came in. There he sat in his wheelchair, crippled with arthritis, spinal cancer, and Parkinsons, unable to see, plagued by the difficult breathing of emphysema, no tactile response because he lost all feeling in his fingers. He was

depressed, demanding and ornery. My Dad's every need had to be met by me or a family member, so now at 4:00 p.m., our 36-hour day would start. Another sleepless night caring for his every need, and I would be exhausted when the alarm would go off at 6:00 a.m.

I called my 16-year-old daughter into my bedroom and said:

> "Laura, Dad and I chose to care for your grandfather. We have had many good times and memories, but now I am at the end of my rope. When I get to be your grandfather's age (he was 80) and am as ornery and demanding as he is, I don't want you and your brother to go through what our family is going through with Grandpa now. Please find a home for me where I will get the care I need and you and your brother will not have to experience the stresses we have all had." (Hopefully, my husband and I have planned and set aside enough money for this purpose.)

She looked at me with her winning smile, and said -- "Do I have to wait for you to be my grandfather's age?"

Thank you!

MONDAY, JUNE 23, 1986

GROUP SESSIONS

GROUP I: ALTERNATE WAYS OF ACCESSING SERVICES/PRODUCTS

Moderator: Saadia Greenberg
Rapporteur: Valerie Bradley

Purpose of the Session

New approaches are needed to assure access to needed service. These approaches could include barter systems, business involvement in discounting needed goods and services, telephone networks, agreements with other service systems, and the development of worksite support and consultation services. This group examined potential ways to determine when different approaches can be used most appropriately and how to stimulate interest in developing and using more approaches.

Participants

The session had an interesting balance of researchers, providers, federal officials, and representatives of national organizations.

What Do We Know About This Area

The discussion of what we know about alternative ways of accessing services and products focused on the following three approaches:

- Barter systems are arrangements where goods and services are exchanged. These projects will help us to determine what it takes to maintain networks and decide whether people are ultimately satisfied with the exchange.

- Workplace consultation and counseling are services provided by the employer to employees who are also caregivers. A survey of workers over the age of 40 indicated that 25 - 30% of those who had some responsibility for the care of an elderly relative perceived these services as useful. However, many corporate workers are not willing to acknowledge that they have problems which the services would alleviate.

- Dissemination. Any information related to the needs of the caregivers may be direct and clear. "How to" ideas were freely exchanged among the participants. This exchange ultimately stimulated interest in exploring issues (e.g., tax credits), solving problems, and developing a strategy that will deal with the caregivers' needs.

What Do We Need to Know About This Area and How Can the Information Be Obtained?

Services

- Research suggests that informal services are not linked with the formal services system. We need to know how best to link the formal and informal services on behalf of families who prefer to care for their relatives.

- Participants suggested that available state and federal resources are not well coordinated on behalf of caregivers. How can caregiver accessibility to needed services be increased in all states? How can federal policies be restructured to offer incentives for states to provide home care without significantly increasing federal costs? We need to develop a multi-agency research agenda that will address fragmentation of services; scrutinize unequal access to and distribution of services; and check the effectiveness of new programs, especially those that have been developed to fill gaps.

- We need to improve caregivers' access to direct services by exploring the use of barter systems, employee assistance programs, corporate volunteers, respite care/day care, environment adaptation, and planning for future financial needs. We need to identify the tax implications of barter systems; assess how these approaches respond to short term (e.g., emergency loans, food assistance, fuel) and long term needs (e.g., home equity conversion, insurance approaches).

Information

- We need to develop information that clearly responds to the needs of discrete audiences. For example, we need to distinguish between information relevant to the recipient of care, to the caretaker, or to the professionals and paraprofessionals who need technical information about behavioral, legal and other issues.

- We need to develop better information sharing techniques such as: information and referral services; newsletters; workplace consultation; support and self-help groups; telephone networks; shoppers guides; public awareness campaigns and caretakers manuals. For what populations are specific information techniques effective? How do people at different economic levels seek information?

- We need to determine the effectiveness of information sharing approaches: how to best communicate relevant information to professionals working with caregivers; and how to use information to help people understand their problems and participate in an informed decision-making process.

- Market research is needed to determine the level of information penetration. This research should assess whether the information reached the target audience and whether they altered their behavior as a result of the information.

Additional Activities Needed

- Reinforce dissemination activities
- Continue to synthesize information
- Increase caregiver participation in the development of strategies

GROUP II: RELIEVING CAREGIVER STRESS AND PROVIDING RESPITE

Moderator: Camille Catlett
Rapporteur: Rhonda Montgomery

This group discussed the major sources of stress and ways to alleviate the stress of caregivers, including differences between particular groups (rural, minority, people suffering from Alzheimers or stroke). The group also discussed the benefits and problems associated with using systems that caregivers may feel more comfortable with (churches). Finally, the group discussed ways to assess the usefulness of different types of respite (in-home, overnight in a foster care setting, and co-op arrangements).

What Do We Know About This Area?

Caregiver stress is not univariate, but multivariate. It can result from factors such as: age, social status, cultural expectations, and the disease condition and severity. Caregiver stress can result from degree of need and/or an individual's personal perceptions of those needs. Caregiving can destroy the emotional balance between the caregiver and care recipient. However, not all caregiving is stressful. It has its ups and downs.

Professionals, providers, and caregivers consider respite an important service for alleviating caregiver stress. Respite is substitute care provided either at home or in another setting for short periods of time. It can be provided as a discrete service, or as part of another service that the family is purchasing. The purpose of respite is to relieve the caregiver of the daily emotional and physical demands of caregiving.

What Should We Know About This Area?

The participants in this session developed a list of needed information.

- How to retool existing services to promote efficient and cooperative respite.
- How to work more effectively with consumers in terms of planning and delivery of services.
- How to improve provider training programs.
- How to appropriately acknowledge and draw upon informal networks.

- How to capitalize on outreach and marketing services.
- How to encourage insurance companies to create policy coverage for volunteer providers.

How Can Needed Information Be Obtained?

- Information can be obtained through the development and analysis of a data base.
- More analysis of the cost/benefit of services.
- Development of research and assessment tools.
- The building of systematic research into demonstration projects to allow for transferability of models and processes.
- Greater focus on research/demonstration mistakes as well as successes so that we can improve future projects and develop a standard approach.

Barriers to the Provision of Respite

- A fragmented and uncoordinated approach to the provision of respite that results from a lack of professional cooperation.
- Denial of a respite need based on caregiver pride.
- Cultural differences (lack of integration into a system of communication)
- A lack of recognition of the differing needs for services of the elderly and the developmentally disabled.

Additional Activities Needed in This Area

The participants chose to focus on useful future activities for the cluster of projects as opposed to activities needed to promote respite. The group endorsed opportunities for researchers, practitioners and policy makers to exchange information and approaches.

GROUP III: CAREGIVER EDUCATION AND TRAINING AND SUPPORT GROUPS

Moderator: Jean Bainter
Rapporteur: Anna Zimmer

Support groups serve two primary functions. They provide an opportunity for caregivers to receive training on how to provide health services, cope with behavioral problems, provide emotional support to the dependent family member, and secure needed services that they cannot provide. They also offer an opportunity for peer support from other caregivers. This group identified needed linkages between formal and informal services and discussed the types of training needed by caregivers.

What Do We Know About This Area?

Caregivers attend support groups to become educated about the problems that they and their family members are experiencing. They also attend to receive training on how to provide care. Caregivers continue to participate in groups because they find the emotional support that they need from people experiencing similar problems.

We know the need for caregiver support will continue to increase with the greying of America and the increased number of developmentally disabled newborns. However, caregivers are underutilizing services and come to groups at a point of crisis after providing care for a long time.

What Do We Need to Know About This Area?

- Does the composition of the group have an impact on its effectiveness (e.g., heterogenous or homogeneous)?
- Does the type of impairment have an effect on the caregiver's willingness and ability to participate in a support group?
- Does it upset those at the early end of a caregiving relationship to hear about problems at the other end?
- Does the sponsorship of the group (e.g., religious sector) determine the type of participants?

- Can support groups provide sufficient linkages to the human service network?

- What outcome do we want as a result of support group participation?

How Can Needed Information Be Obtained?

- Need more data collection on the nature of presently functioning support groups.

- Need a more universally accepted definition of caregiver-- family, friend, neighbor -- amount of care provided, etc.

- A standardized measurement of stress -- relief of stress -- from the viewpoint of the caregiver, care provider and from society's standards.

What Additional Activities Are Needed in This Area?

- Broader-based studies with more standardized instruments.

- If we expect to introduce support groups within the work place, some measure/cost analysis (i.e., absenteeism, quality of work performance) is needed.

- Multi-disciplinary training of human services providers to support the role and needs of caregivers.

- An inventory of services - a hot line - a state level commission on caregiving.

Major Issues Addressed

- How to identify caregivers (help them identify themselves) before they reach crisis.

- How to get the information about existing support services/groups to caregivers and the human services network.

- Dissemination of what we know is not widespread enough. Are caregiver incentives needed? Financial? Services or a combination of both? Service credits?

Major Issues Discussions

- Ethnic differences can be addressed by ethnic staffing in community-based groups, facilitation.

- Nature of the group leadership/professional or mutual aid self help.

- The church needs to assume a more active role with regard to caregiver supports, especially in rural communities.

- Utilization of the media in a more effective way.

Summary and Issues for Further Study

- Education and support groups are one way to relieve caregiver's stress (other options -- individual counselling, day care, respite, etc.).

- We need to report more on what we are now doing in groups -- understand how varied group structure, sponsorship, and facilitation affects caregiver attendance.

- Training of social work, medical, and nursing students should include attention to needs of caregivers.

- What should the federal government's role be?

GROUP IV: PATTERNS OF PROVIDING CARE/HOW FAMILIES ARE MANAGING

Moderator: Kathleen Bond
Rapporteur: Sharon Tennstedt

There is a need for information on how families are providing care to needy relatives. This group addressed such questions as: What are the patterns of caregiving within the population? Which family members are providing care? What specific kinds of care are being provided? How is informal care provided by families related to the use of formal services, including institutional care? What is the prevalence of stress among caregivers? These issues were examined in terms of the types of materials and information that are needed by caregivers and professionals working with them.

What Do We Know About This Area?

The discussion of what we know in the area of patterns of providing caregiving and how families are managing focused primarily on the activities of session participants, most of whom were conducting research on the topic. Consequently, the following discussion is limited, only highlighting aspects of what is known about how families are managing. We heard from researchers studying patterns and outcomes of caregiving as well as various intervention strategies designed to assist caregivers (by information dissemination, skill development, or support/stress reduction). Most of those present were engaged in research and activities related to the giving of care to older relatives, although researchers in the area of special child care were also represented.

We know that family caregivers are primarily women, mainly wives and daughters. However, there is an increasing recognition of the important role and special situation of spousal caregivers, typically one-half of whom are men. Spouse caregivers are usually the sole caregiver and are less likely to utilize formal services.

We know that caregivers perform a wide variety of caregiving activities which are often found to be gender related with women performing more personal care and men performing financial management and home maintenance.

In terms of amount of care provided, in studies which have looked at formal service utilization as well as informal care, informal care outweighs formal services. The National Long-Term Care Survey shows that less than ten percent of caregivers use formal services. However, other studies using representative samples show that living arrangements are related to the use of formal services,

with those living alone using more services. There is little evidence for a "substitution effect" of formal services replacing informal care; rather a complementary pattern is found. The primary predictors of amount of care provided are proximity of caregiver, sex of the older person (men receive more care) and level of impairment. Employment status does not seem to influence amount of care, as employed offspring provide as much care as those who are not employed.

The discussion of how care is provided questioned the assumption of a caregiving network. By and large, caregiving is not a shared task -- most care is provided by a primary caregiver (although there is some evidence of sharing among female siblings or by other members of the primary caregiver's nuclear family).

Increased attention is being paid by the research community to the consequences of caregiving for the caregiver with a focus on perceived burden, stress, and mental health outcomes. Evidence of depression among caregivers has been reported in several studies, and this appears to be especially so among caregivers of Alzheimer Disease patients. There are inconsistent findings regarding gender differences here. The nature and extent of behavioral problems of the patient are often associated with reports of stress or negative consequences of caregiving.

The intervention studies reported on in our session are in progress with only preliminary results available. Approaches addressed include information dissemination, skill development or coping mechanisms, and supportive services including various forms of respite and support groups. Some projects are comparing approaches. One project has shown that families can be trained to improve some of the problem behaviors associated with the illnesses of their older relatives through the use of reinforcement for positive behaviors, stimulus cuing of positive behaviors, and contracts specifying expectations of both the caregiver and the impaired older person.

Some research is looking at patterns of caregiving among female blue-collar workers and at the policies of work organizations concerning insurance and leave policies for elder care. This work is still in progress. A preliminary finding is that caregivers often do not have knowledge of the formal services available to them. A national survey of corporate employers and their elder care policies is being undertaken.

What Do We Need to Know About This Area?

Research shows that the family is the major system for emotional support as well as care for older people. Yet the family itself is undergoing many changes: an increasing number of generations in families, with four or five generations alive at the same time; in recent decades, nuclear families are decreasing in size; rates of divorce and remarriage remain fairly high and result in a proliferation of kin and complicated family structures; and female labor force participation rates are continuing to rise. Continued research is needed on how family environments (and changes in family environments) will affect the quality of intergenerational relation-

ships, influence the family's support capabilities, and affect norms for independent living for older people and for young adults who need protective environments. Additional research is also needed on family caregiving and on the relationship between formal and informal care.

Examples of research topics which continue to need attention are:

- Projections of the future functional status of the older population
- Projections of available kin for the future care of older people. Basic research in family demography is needed. In the U.S., we have produced detailed data on households, but less information on families, particularly on multigenerational families.
- We need information on how families cope with caregiving over long periods of time with attention given to the health and functioning of caregivers as well as care recipients. At what point and under what conditions are formal services accessed? Longitudinal studies are needed.
- We need to know more about the roles family members are playing in interviewing and coordinating with the formal health care system on behalf of older patients and how their efforts are related to the maintenance of health and functioning. We also need to alert our health care personnel to the research on family caregiving and to the importance of families in the provision of care.
- We need to know more about (and to increase) the knowledge that family members and older people themselves have about the aging process and the problems of older people, and how this knowledge relates to decisions to seek health care or to follow disease prevention practices. Too often older people and their families accept the myth that aging is inevitably accompanied by disease and disability. These myths may be related to acceptance of symptoms and disabilities and the postponement or avoidance of health care. We need more research on health behaviors and attitudes in relation to aging.
- We continue to need research on special categories of caregivers -for example, old children caring for even older parents, older couples who are caregivers for each other, and caregivers who are providing care from a distance. We need more analyses based on the dyad of caregiver - care recipient, and on ways of training, supporting, and helping caregivers.

TUESDAY, JUNE 24, 1986

OPENING PLENARY SESSION

PERSPECTIVES ON FAMILIES - INTERNATIONAL CAREGIVING

Heather McKenzie

We need to remember that there is already research and written comments on many of the areas currently being considered for investigation.

We can learn from the system that is used in the United Kingdom. The following describes the fundamentals of the United Kingdom's system - statutory, voluntary, and increasingly, the private sector's roles.

- The District Health Authorities and Social Services Departments account for medical, nursing at home, home help, housing, social services, nursing and residential care facilities. They also include rehabilitative services and financial benefits.

- The voluntary sector accounts for lunch clubs, housing, sitting in, and meals on wheels schemes.

- The private sector is increasingly involved in residential/nursing care provision, home income plan schemes, and respite schemes.

Considering the above, why then is care still essentially familial supported? Because of the reluctance of families to get involved with the system; because of their ignorance of the existing services; and because they have not been educated to appreciate that they will better cope with service support.

What role did NCCED play in the development of the existing resources?

This organization campaigned for financial benefits; built special needs pilot scheme housing funded by government grants; introduced the granny sitting concept; produced an adopted and adapted career guide to support personnel/services; set up a nationally recognized advisory service; worked consistently on bringing the whole topic into public policy focus through media programs, features, research, and books; drew up a home careers educational module; had 46 large groups which were encouraged to be information resources at the local level and to foster self support; and lectured to involved professionals and employees/employers.

How can the private sector become involved in the U.S. scene?

Private employers can develop employee programs which emphasize coping mechanisms and obtaining access to support services and professional assistance. They can also make leave available for specified periods based on evidence of need. Employers could cooperatively compile and publish data on regional supportive services/personnel. Benefits could include respite schemes, retiree welfare programs, and special needs housing.

- We can pursue the development of a system from hereon in the U.S. The fundamentals of a well-functioning system can be based on:
- Assessed need - physiological, emotional, and social
- The establishment of a resource data bank on a regional level
- The establishment of an advisory service
- The development of an educational program on good home caring models
- The development of an integrated system with client/familial input
- The promotion of health screening and enhancement of residual abilities programs
- The introduction of regulations for guaranteeing nursing/long-term care home practices
- The introduction of hospital release programs which support the former patient
- A cognizance of different ethnic needs
- The development of respite programs which accommodate differing needs.

Account must be taken of the following in any restructuring and planning:

- The increased median age of caregivers
- The increase in the number of working women
- The increase in the number of fragmented families
- Different coping levels among men/women
- The de-emphasis on intergenerational acceptance
- Historic familial patterns
- The need to promote positivism

- The establishment of a clearinghouse of research findings/projects to avoid duplication/overlap.

CONSUMER-DIRECTED PREVENTIVE SERVICES

LIFE SERVICE PLANNING

Debbie Zuckerman

Community services, if used constructively in conjunction with a person's own resources, and with sufficient forethought in planning for future needs, can assure the aging, disabled, or handicapped individual a range of protective health and social services that will prevent premature institutional placement or inappropriate guardianship. However, community services have historically been concentrated on severely dependent individuals living in institutions or under legal guardianship. At present, there are few middle options when totally independent living is no longer possible and the prospect of institutionalization and/or adjudication of legal rights approaches. Because the present transition between relative independence and institutionalization is too often abrupt and traumatic, a middle range of consumer-directed services that can prolong relative independence in the community, postpone institutionalization, and prevent guardianship needs to be developed. The demonstrations of consumer-directed services funded by the Office of Human Development Services will:

- Identify alternative methods for developing and promoting consumer-directed service plans;
- Identify alternative personal financial arrangements available to support a consumer services plan including pre-paid membership, long-term care insurance, home equity conversion, or monthly service fees;
- Identify the characteristics of organizations capable of promoting and implementing service plans;
- Describe consumer attitudes concerning life-term services and financial planning;
- Explore the role of organizations responsible for implementing the plan when the client becomes incapable of directing the plan alone; and
- Describe how relationships with existing community services organizations and parent groups can help to secure services under the plan.

The projects identified below are part of this effort.

American Bar Association - "Life Service Plans for the Elderly and the Developmentally Disabled." This project will: a) develop a financial training package; b) develop training materials on financial, estate planning and alternative supervisory arrangements that are available for the at-risk elderly; c) test the above materials; and d) disseminate materials to other communities and agencies.

Older Americans Consumer Cooperative - "Independent Living Program." This group will: a) demonstrate a life services planning program to include financial planning, home equity conversion, group purchasing, consumer information, counseling and peer advocacy; b) target diverse or low socio-economic and racial groups in the Washington, DC area; and c) produce training materials and computer software programs to facilitate replication.

Center for the Public Interest - "Guardianship, Conservatorship and Institutionalization Diversion." This project will: a) design and pilot a guardianship diversion program to serve the frail elderly; b) provide an alternative to the present system in which problem clients or clients in need of sustained protective involvement are institutionalized or placed under court or public guardianship; and c) nationally disseminate T.A. material.

Planned Lifetime Assistance Network (DD) - "Community Based Care and Services Planned Lifetime Assistance Network Program to Develop Personal and Resource Plans for the Handicapped." This program will: a) assist families to develop and effectively utilize the resources of the family member; b) develop a long range resource plan; and c) develop a personal assistance plan for the handicapped family member.

La Clinica Familiar del Barrio - "The Linkages Program: Natural Networks for Life Services Plans Through Community Organizations." This project plans to: a) involve small businesses, financial institutions, congregations, etc. in developing volunteer programs and local fundraising to strengthen informal support resources; b) develop life services plans for 70 people; c) involve the informal networks; and d) train graduate students in community organization and counseling skills to increase informal support for the elderly.

East Arkansas Area Agency on Aging - "Consumer-Directed Life Plans/Options for Elderly Parents with Developmentally Disabled Dependents." This project will: a) develop and implement life care planning options for parents aged 60 and older with adult developmentally disabled (DD) dependents; and b) develop, conduct, and evaluate training for both the aging and DD networks to prepare for this project and for ongoing cooperative intervention for target families.

Huntington Memorial Hospital - "Develop and Test a Life Services Planning Model." This model focuses on the role of the individual, and the use of private sector legal and financial resources in preventing unnecessary loss of independence. The project will have three phases: a) research the literature for planning models and identify factors leading to dependency; b) develop and refine the model; and c) implement the program.

New York City Department for the Aging - "Alzheimer's Legal Support Project." This project will: a) train law students, lawyers, and Department for the Aging staff on legal issues related to the needs of Alzheimer's patients and caregivers; b) provide legal and financial decisions; c) implement public education strategies to increase caregiver awareness of the need for long-range legal and financial planning; and d) enhance the ability of AAA's and the aging network to assist Alzheimer's patients and caregivers.

CAREGIVERS OF THE FRAIL ELDERLY: A NATIONAL PROFILE

Dr. Robyn Stone

An examination of the data from the 1982 National Long Term Care Survey reveals that informal caregivers to the disabled elderly are predominantly female and that three quarters of them live with the care recipient. The data suggest that caregivers as well as care recipients are a vulnerable group since one third are over age 65, report incomes in the poor to near-poor category and describe their health status as fair or poor. Less than ten percent of the caregivers purchase services. There is also evidence of competing familial and employment demands among a subgroup of caregivers.

Some highlights of this data analysis are presented below.

Who Are The Caregivers?

- Almost three-quarters are female (29% daughters and 23% wives); 13% are husbands.
- Average age is 57.3 years; one-quarter are aged 65 to 74 and 10% are aged 75 and over.
- Approximately 70% are married; among daughters, 56% are married, 14% are widowed, and 16% are divorced or separated.
- Three-quarters live with the care recipient; 60% of daughters and sons live with care recipient.
- One-third of the caregivers are working.
- One-quarter rate their overall health status as excellent; one-quarter rate their health as fair or poor.
- One-third report poor or near poor income (adjusted family income). 60.4% of wives and 55.4% of husbands are sole providers; 23% daughters versus 11% sons are sole providers. One-third provide care with no assistance; 10% purchase formal services; and 29% are secondary caregivers.

Who Do They Care For?

- One-fifth of the care recipients are 85 years or older with an average age of 77.7 years.
- 60% of the care recipients are females.
- 50% are married and 41% are widowed.
- Approximately 11% live alone.
- One-third are poor or near poor.
- 38% rate their general health as poor.
- One-fifth report no Activities of Daily Living Skills (ADLS) limitations; 13% report 5 or 6 ADLS limitations.
- 29% report 3 or less ADLS problems; 18% have 8 or 9 ADLS limitations.

Additional findings: Caregiving is gender-linked; that is, while the majority of care is provided to females, daughters and other female caregivers are more likely than male counterparts to be caring for elderly women.

Caregiver Commitment

- One-fifth of the caregivers have been providing care for five years or more; 18% less than one year, 44% one to four years.
- 16% ceased providing care during the three-month interval between sample selection and the interview (one-half died; one-fourth institutionalized).
- 80% provide care seven days per week.
- On an average day, caregivers report spending four extra hours on caregiving tasks. Husbands reported spending the most hours, with an average of five extra hours per day.

Caregiver Tasks

- Two-thirds provide assistance with one or more of the following ADLS: feeding, bathing, dressing, and toileting; daughters are more likely than sons.
- 46% help the disabled person get around inside and/or get in and out of bed; husbands are more likely than wives.
- 53% administer medication.
- 86% spend extra time with shopping and/or transportation.

- 80% spend extra time performing one or more household tasks including meal preparation, housecleaning and laundry; husbands are more likely than wives.

- 50% spend time handling finances; wives are more likely than husbands to do this.

Competing Demands

- One-fifth of the overall caregiver population and one-quarter of the caregiving children had children under the age of 18 living at home.

- 9% left the labor force to become a caregiver (13.5% of wives; 12% of daughters).

- Among the one million caregivers who had been employed at some time during the caregiver experience:
  - one-fifth cut back on hours;
  - 29% rearranged work schedules; and
  - 19% took time off without pay.

Who Purchases Services? (less than 10%)

- Primary caregivers who are working

- Primary caregivers with high family incomes

- Primary caregivers with responsibility for more severely impaired persons

Also, husbands are more likely than wives to purchase services (16% versus 9%).

CHANNELING EFFECTS ON INFORMAL CARE

Robert Clark

In September, 1980, the National Long Term Care Demonstration -- known as channeling -- was initiated by three units of the United States Department of Health and Human Services. It was to be a rigorous test of comprehensive case management of community care as a way to contain the rapidly increasing costs of long term care for the elderly while providing adequate care to those in need.

The Intervention

Channeling was designed to use comprehensive case management to allocate community services appropriately to the frail elderly in need of long term care. The specific goal was to enable elderly persons, whenever appropriate, to stay in their own homes rather than entering nursing home care expenditures. It had no direct control over medical or nursing home care expenditures. It financed direct community services, to a lesser or greater degree according the channeling model, but always as part of a comprehensive plan for care in the community.

The core of the intervention consisted of seven features:

- **Outreach** to identify and attract potential clients who were at high risk of entering an institution;
- **Standardized eligibility screening** to determine whether an applicant met the criterial (i.e., age 65 or older; functionally disabled according to ADL measures; having unmet needs; and living in the community;
- **Comprehensive in-person assessment** to identify individual client problems, resources, and service needs in preparation for developing a care plan;
- **Initial care planning** to specify the types and amounts of care required to meet the identified needs of clients;
- **Service arrangement** to implement the care plan through provision of both formal and informal in-home and community services;
- **Ongoing monitoring** to assure that services are appropriately delivered and continue to meet client needs; and
- **Periodic reassessment** to adjust care plans to changing client needs.

Two models of channeling were tested.

The basic case management model relied primarily on the core features, using existing providers but providing a small amount of additional funding to fill gaps in existing programs.

The financial control model differed from the basic model because it expanded service coverage to include a broad range of community services; established a funds pool so services could be allocated on the basis of need and appropriateness rather than on the eligibility requirements; empowered case managers to authorize the amount, duration, and scope of services; imposed two limits on expenditures from the funds pool (average client expenditure could not exceed 60 percent of the average nursing home rate in the area, and expenditures for the individual client could not exceed 85 percent of that rate without special approval); and required clients to share in the cost of services if their income exceeded 200 percent of the state's Supplemental Security Income eligibility level plus the food stamp bonus amount.

Results on Informal Caregiving in the Channeling Demonstration

Two sources of data underlie this analysis. The first is responses of elderly sample members to questions about their receipt of care and financial assistance from all informal caregivers. The second consists of responses to a more detailed set of questions asked of the person designated by the sample member as their primary informal caregiver.

Caregiving Patterns at the Start of the Demonstration:

- 83% (basic model) and 78% (financial control) reported having some care provided by an informal caregiver.
- The most frequent type of assistance was help with housework, laundry, or shopping (79% and 74%) and meal preparation (69.7% and 64.4%).
- Help with medical treatments was the least common (14.4% and 12.6%).
- Sample members received about four visits a week from informal caregivers. These totaled 10-11 hours a week, more than half of which were devoted to providing personal and housekeeping care.
- Three-quarters of the primary caregivers were female, between the ages of 58-60 and in good health.
- About 45 percent provided some financial assistance to sample members, averaging $80-$85 per month (about twice that if only those caregivers providing assistance are included).
- About two-thirds of the caregivers reported limitations on their social lives due to caregiving.

- The stress experienced by primary informal caregivers appeared to be substantial, with more than one-third reporting that they experienced severe emotional stress, and about the same proportion expressing dissatisfaction with their lives.

Effects on Informal Caregiving

- There was no evidence that channeling under the basic case management model led to substitution of formal for informal care.

- Channeling under the financial control model did lead to modest substitution of certain services, but there is no evidence of overall substitution on a wide scale. Nor is there evidence of reductions in informal care provided by primary caregivers. The effect appears to be due primarily to withdrawal of some friends and neighbors.

- The services for which there was evidence of some substitution under the financial control model included: meal preparation; housework, laundry, or shopping; general supervision; delivery of prepared meals; and help with transportation. In all cases, the rates of substitution were modest.

- Evidence of substitution was also found under the financial control model for three broader measures of informal caregiving: number of different services provided, percent of sample members with a caregiver, and number of visiting caregivers. For these measures, reductions in informal care were again small. Furthermore, no substitution effects were detected for the number of visits and hours of care received, both presumably more comprehensive measures of overall caregiving effort.

- There is some suggestion that channeling led primary caregivers to concentrate their efforts in certain areas. First, for elderly sample members living in the community, channeling under the basic case management model increased caregiver involvement in arranging services or benefits. Second, channeling under the financial control model increased the frequency with which primary caregivers reported providing help with eating and cleaning up after bowel and bladder accidents and with arranging services and benefits.

Effects on the Well-Being of Primary Informal Caregivers

- Channeling improved the well-being of primary caregivers by some measures.

- Channeling under the basic case management model reduced the percent of caregivers who perceived limitations on their privacy and social life. (At six months, for the sample living in the community under the basic model, 8.8 percent of the treatment group caregivers perceived restricted privacy as a serious problem versus 15.9 percent of the control group caregivers).

- Channeling seems to have somewhat reduced caregiver worry about obtaining sufficient help under both models.

- Channeling under both models increased the overall life satisfaction expressed by primary caregivers. At six months, for example, for the sample in the community under the basic case management model, 20.9 percent of treatment group caregivers found life not very satisfying versus 29.9 percent of the primary caregivers in the control group.

- There is little evidence that channeling reduced caregiver perceptions of the degree of emotional, physical, or financial strain they experienced due to caregiving.

A more comprehensive report about the impact of channeling on informal caregiving is available.

TUESDAY, JUNE 24, 1986

GROUP SESSIONS

PRIVATE SECTOR FOUNDATION AND SMALL BUSINESS SUPPORT FOR FAMILY CAREGIVING

Moderator: Deborah Bass
Rapporteur: Carolyn Asbury

The benefit from supporting family caregivers is more than monetary. Current evidence suggests that enhancing the quality of family life results in substantial benefits to the larger society. These benefits include increased family self-reliance, maximization of family cohesiveness, and improvements in the productivity of individual family members. Increasingly, the private sector (foundations, small businesses, national corporations) is investing, both ideologically and financially, in supporting family caregiving, both at home and in the workplace. The purpose of this group was to explore the possibilities for private sector involvement, including mechanisms and approaches which can be identified to enable primary caregivers to fulfill their caregiving responsibilities and still be able to sustain their financial independence by gaining or maintaining employment.

The primary participants from the private sector were three foundations (Dole, Robert Wood Johnson, and Retirement Research). So the discussion primarily centered around foundation priorities and plans for the future.

What Do We Know About This Area?

- Programs which are funded by both the public and private sectors often address the same or similar issues in areas such as caregiver stress, caregiver needs, the use of assistive devices and the development of structured programs.

- In many areas, we know a great deal. However, we need to improve dissemination of useful models.

What Do We Need to Know About This Area?

- The appropriate roles and relationships among volunteers, the private market, and public programs.

- How we should change the financing mechanisms that drive the service system.

- How to bring researchers and service providers together in a meaningful way that serves both; ensure that the research component is in place before a demonstration project begins so that we can get accurate information on what works and how it can be transferred to other sites; and help researchers to understand the intended functioning and outcome of programs before they begin designing studies.

How Can We Obtain the Needed Information?

- We need to cooperatively identify the most effective ways to gather and present relevant information and disseminate it to policy makers, researchers and practitioners. Representatives of these different groups have a responsibility to let us know what information and presentation format are most useful.

- Funding agencies need to develop collaborative research, demonstration and evaluation plans in every service demonstration. These plans would assure the selection of research projects that have program applicability and transferability.

Major Unresolved Issues

- On one hand, the private sector provides adequate services when an individual or family has ample resources to pay for services. On the other hand, in some places, government support provides only a minimum number of services to those who do not have any resources. How can we get the public and private sectors to work together in a way that reduces the inequitable two-tiered system?

- How can agreements be made routinely between government agencies and foundations for cooperative funding of projects in areas of mutual interest? Often the private foundations are seeking a separate clientele and/or public agencies are quick to withdraw their funding if foundations provide funds for similar areas or clients. Also, the foundation funding cycle usually runs for 4-5 years, while federal agencies do not know what funds will be available from one year to the next.

- How can the development of small businesses be encouraged in areas that will fill gaps in service availability in individual communities? One example given was of a business that is trying to develop a wrist dialysis unit.

- How can foundations and small businesses work together? Foundations are nonprofit organizations while businesses are looking for a health profit. Suggestions were made that foundations assess subcontractual needs and keep small businesses in mind.

Plans For the Future

The three foundations identified multiple and varied plans for funding projects in the future. Project areas will include: employment of disabled persons; operationalizing the personal autonomy concept; assessing differences in caregiver adjustment to stress when they are caring for individuals with different types of illnesses (e.g., cancer or Alzheimers); and increasing decision-making on the part of older persons.

The Retirement Research Foundation also plans to continue their national media awards program. This program provides recognition to producers of media events who address issues of concern to older people. It does not involve any monetary compensation.

Participants emphasized the need for better caregiver education and training. No immediate plans were described except for a proposal from the American Society of Aging to develop a national training center for practitioners who then train caregivers.

PUBLIC POLICIES AND FAMILY CAREGIVING

Moderator: Cleonice Tavani
Rapporteur: Richard Shute

It is estimated that the cost to taxpayers for the care of persons with developmental disabilities exceeds eight billion dollars annually. The cost of caring for elderly persons in need of extended care exceeds thirteen billion dollars each year. Funding sources include federal programs such as Title XIX (Medicaid), Title XX (Social Service Block Grants) and Supplemental Security Income (SSI), as well as dollars raised through state and local taxes. But should family support services for this and other vulnerable populations be justified because of their ability to save tax money; or is the goal of improved quality of life for the family and the person with disabilities a sufficient objective? This group considered existing policies at the national, state, and local levels that reflect progress toward the development of comprehensive family caregiving policies. The group also discussed the way in which the private sector should be involved in the policy making process.

What Do We Know About Public Policies?

The major federal assistance of families caring for chronically impaired members is the Social Security program with its income transfers to the elderly, the disabled, and their survivors. Financial aid to the disabled and minor survivors are very obvious ways of assisting in their care. Social Security retirement benefits enable the elderly to lead more independent lives and, therefore, not be a financial burden on their younger relatives. At the micro level, federal aid ranges from cash benefits such as the aid-and-attendance program of the Veterans Administration to financing a wide range of health and social services.

Social services are also available through a variety of programs such as the Social Services Block Grant, Older Americans Act, and Medicaid. Aside from the Older Americans Act, these services are usually available dependent on the income and assets of the impaired person. If the impaired person is a minor, services are available contingent upon the income of the parents.

Participants agreed that directive government policy is associated with government funded activity.

What Do We Need to Know in the Area of Public Policy?

- How to determine when direct cash payment or the provision of services is the preferred option. States have been experimenting in recent years with cash payments for persons in need of care from another. However, no significant data are yet available on the merits of cash transfers as opposed to the provision of direct service. Anecdotal information from current caregiver demonstrations indicates that families often prefer services such as respite to cash benefits. (However, it appears that this preference may apply more

to families caring for an elderly relative than to those caring for someone who is developmentally disabled).

- How to evaluate the degree of burden felt by family caregivers and how public funds can best be used to alleviate that burden. Workshop participants agreed that families were not overwhelmed by caregiving for the most part, and did not make unreasonable requests for relief and respite from their caregiving functions.

- How to make services flexible and responsive to crisis needs.

- How to work together with the consumer movement, so that advocates help to educate caregivers and assess the adequacy of services; and so that professional associations develop service standards and institutionalize them through college curricula. Through early planning for future service needs, unnecessary dependency and related family caregiver stress can be reduced.

- How to inform employers about the corporate advantages of employee assistance programs so they will invest in the development of employee benefits and services. Early study results indicate that understanding and assisting workers who have excessive caregiving responsibilities can increase productivity.

Participants agreed that we need to focus on future problems before they occur and develop preventive strategies.

Conclusion

The Family Caregiving Project, as a pro-active interchange among federal agencies and with private organizations, offers an opportunity to develop a unified, preventive approach to dependency and unnecessary stress.

CLOSING PLENARY SESSION

Chairperson: Carol Fraser Fisk
Commissioner on Aging

Due to the number of high level departmental officials and association executives who participated in this session, it was not feasible to report all of their comments. Consequently, only highlights of their remarks are presented here.

Structure of the Session

Each rapporteur from the small group sessions presented highlights of their discussions and recommendations (discussed earlier in these proceedings). Association executives then briefly had an opportunity to provide reactions and discuss their association activities in this area. Following their comments, departmental officials summarized their reactions and described the types of grants awarded by their agencies. A list of all participants can be found in the Appendix.

Association Reactions

Most association executives were pleased that the conference brought together researchers, practitioners, and policy makers. They found it to be a useful vehicle for discussing joint concerns.

Most of these executives responded to one of the problems identified by conference participants, that is, the need to better disseminate information. The association participants agreed that a cooperative effort would be needed to inform family caregivers, and the professionals, paraprofessionals and volunteers who work with them, about available resources and new approaches for assisting caregiving families. Many committed their organizations to assisting in this effort by disseminating information through their newsletters and conferences. Some also offered to develop continuing education curricula and standards for their members who work in this area. Some also indicated a willingness to participate in a public education campaign designed to encourage the prevention of lifestyles that lead to chronic functional disabilities, and to reach caregivers to let them know about available assistance.

Some of the association participants expressed concern about the federal policies which provide financial incentives for families to institutionalize impaired members. They asked that the departments work on changing these policies -- particularly the disincentives to home care found in the SSI and Medicaid programs. One association representative felt that the Medicaid program also discourages preventive planning and the purchase of appropriate insurance.

Departmental Reactions

Most departmental officials agreed that the conference format was useful.

Some departmental officials felt that the conference recommendations indicated a need for more effective measurements of stress and the impact of various approaches on reducing stress and supporting caregivers. These participants made a commitment to continue to develop measures and to research caregiver service needs and the responses of the informal and formal systems.

Departmental participants also made a commitment to continue to work together to resolve the problems of families with an impaired member by: 1) participating on a work group to share information and approaches among federal agencies; 2) disseminating information to caregivers and people working with caregiving families; and 3) continuing to bring grantees together to share experiences -- both problems and successes.

Conclusion

Carol Fraser Fisk, Commissioner on Aging, closed the conference by saying that her department would follow-up on commitments made, and pledged that the Administration on Aging will continue to work on behalf of family caregivers.

APPENDIX

List of participants - categorical

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